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Birth and Pregnancy Termination Rates in The United States Since Perinatal Hospice Law Establishment

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Birth and Pregnancy Termination Rates in The United States Since Perinatal Hospice Law Establishment

By

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The Clinical Research Project is offered as an elective for MSW students at St. Catherine University – University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted to demonstrate facility with basic social research methods. Students must independently conceptualize, and implement a research project, as well as publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

Design. The purpose of this study was to find out if perinatal hospice laws have changed termination of pregnancy (TOP) rates due to fetal abnormality. This research applies secondary data analysis to determine if establishing informed consent laws have impacted these variables.

Findings. TOP rates due to fetal abnormality appear to have changed after enactment of perinatal hospice laws, however these results may be due to chance because the findings were not statistically significant. The average rate of TOP due to fetal abnormality was higher in states without perinatal hospice laws (M=710.67) than in states with them (M=243.33).

Implications for social work practice. Perinatal hospice allows parents to understand their baby's diagnosis, prognosis and are able to exhaust medical intervention options. An abnormal fetal diagnosis is an unexpected journey and unimageable for many people. Medical professionals need to be willing to walk alongside families during this challenging life experience. Continuing or terminating a pregnancy in this type of situation has social justice issues woven deeply into the medical intervention decision.

Key terms: Birth Rate, Abortion, Perinatal Hospice, Informed Consent

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The leading cause of infant deaths in the United States is due to congenital malformations, deformations and chromosomal abnormalities (Calhoun, 2010; Mathews, MacDorman, & MacDorman, 2013; Mathews, MacDorman, & Thoma, 2015). These disorders lack a reasonable hope of being cured and can be fatal depending upon severity. An ultrasound done during the first trimester of the pregnancy is able to detect many major structural abnormalities (Coleman, 2015). Ultrasounds during pregnancy is common practice for monitoring purposes. It allows for screening of potential complications, an initiation of a medical intervention and to support the mental health of the mother (He, Akil, Aker, Hwang, & Ahmad, 2015).

Developments within prenatal diagnostic abilities have emphasized a lack of medical intervention choice for parents when an abnormal fetal condition is detected (Calhoun, 2010). Parents have complex reasons behind choosing to continue or terminate their pregnancy after a diagnosis of fetal abnormality. The community in which they live, family, friends, health care providers, financial resources, needs and values are a few variables considered when making this incredibly difficult choice (Cobb, 2015). It has been found that health care providers tend to not empathize or understand why a pregnancy like this would be continued. Coleman (2015) reported 61% of parents felt pressured to terminate their pregnancy despite voicing to the provider that they wanted to continue their pregnancy. Termination of pregnancy (TOP) is a widely supported and chosen medical intervention for fetal abnormalities (Lotto, Smith, & Armstrong, 2017).

It is thought that TOP averts feelings of guilt, despair, avoidance and depression (Cope, Garrett, Gregory, & Ashley-Koch, 2015). There is no evidence that TOP reduces ‘healthy’ or pathological grief (Côté-Arsenaulta & Denney-Koelschb, 2016). Cope and colleagues found a

significant increase in despair, avoidance and depression among women who chose TOP as a medical intervention as compared to the women who chosen to continue their pregnancy. Male participants reported grief, anger and helplessness, after a terminal fetal diagnosis in which TOP was picked as a medical intervention. These participants reported feeling being forgotten by providers and society (Cope et al., 2015). However, a study in the United States found it psychologically beneficial to continue the pregnancy following a terminal fetal diagnosis (Cope et al., 2015).

Perinatal hospice, an alternative to TOP, allows parents to create and enjoy moments with their child as well as create a birth plan. A mother who participated in perinatal hospice programming noted "The anesthesiologist grabbed my camera and he took a video, which I would have never thought of, so we have her on video, alive" (Kamrath et al., 2018). Parents can also explore and outline meaningful family experiences, which provides positive memories. "We're going to hold her and the whole family is going to come in here…and we can pass her around. We can talk and smile, and we can take pictures" was quoted by a family in the Kamrath et al. study (2018). This programming provides opportunities for parents to make memories with their preborn child. The support given by the medical team creates an environment that allows parents to identify as mom and dad and for the family to begin the grieving process in a healthy way (Edwards, 2018). As reviewed, research seems to have mixed results regarding the outcomes for families who choose TOP as a medical intervention option and those who choose to continue the pregnancy. Masiach et al. (2013) reported women who chose to terminate their pregnancy due to fetal abnormality reported anxiety on the day of the termination, grief and anxiety at their ten week follow up appointment followed by a period of gradual anxiety

reduction, however this study also noted that grief and anxiety can persist for a long time and continuing psychosocial support is necessary for those impacted.

Perinatal Hospice Model

The goal of perinatal hospice is to strengthen family relationships during this unfortunate situation (Coleman, 2015). It empowers families to influence their outcome for the better. After a terminal diagnosis, parents have tended to experience feelings revolving around fear, isolation and abandonment (Coleman, 2015). They may be unaware of available medical interventions or potential aftereffects of chosen interventions. Kamrath et al. (2018) use a model that includes expert and personalized care from an interprofessional team, choices of medically appropriate interventions and a legacy framework that focuses on the infant, family and larger community. Legacy framework refers to the collection of memories accumulated by families while care is provided, choices are made and moments experienced (Kamrath et al., 2018). They found frequent visits for questions from the interprofessional team allows for manageable amounts of information and noticed the importance of supporting opportunities for memory making within the whole family (Kamrath et al., 2018).

Clinicians often consider perinatal patients diagnosed with a terminal or severe and irreversible cognitive disability as a dying patient (Gawron & Watson, 2017). Hospice is a method of care for an individual at end of life stages using a combined team approach. The guiding philosophy in hospice is for patients to die pain free and with dignity while extending emotional and spiritual care to family members (Lindley & Newnman, 2017). Perinatal hospice is similar to hospice in that the medical team focuses on relieving pain and uncomfortable symptoms the infant may experience while extending emotional and spiritual support to family. It is distinguished from hospice because the care of the infant begins prior to birth and supports

opportunities for family memory making, both before and after delivery (Kamrath et al., 2018). Parents are provided the opportunity to complete a birth plan, which outlines rituals that are desired post birth. Examples include the baby being baptized or the parents giving their baby a bath. Parents are able to parent by influencing quality of life and outlining care and comfort measures (Cobb, 2015). These unique factors are distinct due to the dual focus of the preborn infant and the family.

History of Perinatal Hospice

The foundations of hospice and palliative care was established by religious institutions supporting those near death and has evolved over the past thousand years (Lutz, 2011). Cessation of life was and still is viewed as a natural process. The central forms of palliative and hospice care were extended to perinatal medicine after families anticipating perinatal loss were found to resemble families of a terminally ill adult (Coleman, 2015). Perinatal palliative care is an umbrella term for treating discomfort and distress associated with an abnormal prenatal diagnosis. It includes comprehensive care incorporating the care of the patient with a life limiting condition and extending to the entire family (Pfeifer, Gubler, Bergstrasser & Bassier, 2018).

Perinatal hospice, which includes perinatal palliative care, incorporates an interdisciplinary team to provide support that includes education, which includes discussing medical interventions and development of a plan of care based on family wishes. Support given by health care professionals during this type of pregnancy has been found to be important for the parents' emotional health (Coleman, 2015). Given the long-standing tradition of hospice and the benefits of perinatal hospice, it would seem that perinatal hospice laws would generate an increased use of this service. It is hard to determine the impact laws have on society and this research makes an attempt to clarify if establishment of perinatal hospice laws have impacted birth and pregnancy termination rates within the United States.

Research Design

The purpose of this study was to find out if perinatal hospice laws have changed birth and TOP rates after a terminal prenatal diagnosis is made. The central research question asks if perinatal hospice laws have impacted abortion rates after a terminal prenatal diagnosis. While the four associate research questions ask if states with perinatal hospice laws have a different rate of TOP due to fetal abnormality than states without the laws, if states with perinatal hospice laws have different birth rates than states without the law, if TOP rates due to fetal abnormality have changed in states with perinatal hospice laws after it was enacted and if birth rates changed in states with perinatal hospice laws after enactment of the law. This research applied secondary data analysis to determine if establishing informed consent laws have impacted these variables. That is, using existing data generated by government agencies and available to the public to answer the research question as to whether perinatal hospice laws have impacted birth and TOP rates after diagnosis of a fetal abnormality (Grinnell, Williams & Unrau, 2016).

The chosen datasets assisted in answering if perinatal hospice laws have changed birth and rates of TOP due to fetal abnormality. Potential changes in birth and TOP rates after a terminal prenatal diagnosis could be due to parents being made aware of perinatal hospice and choosing this as a medical intervention. Some parents may decide to continue their pregnancy that may have otherwise chosen TOP because they did not know an alternative intervention existed. Birth and abortion rates could then change with these dynamics.

Variables. The variables in this study were birth rates and TOP rates after a terminal prenatal diagnosis. The perinatal hospice law was the variable controlled for. The causal relationship of birth rates and the rates of TOP due to a fetal abnormality were explored between states with and without perinatal hospice laws (Shadish, Cook & Campbell, 2002).

Statistical Measurements. The three statistical measurements that were taken in this research project were two sample t-test independent samples, interrupted time series and paired samples t-test dependent samples. A two sample t-test -independent-samples obtains one measurement, which is split into two groups and then compares the average measurement of two data groups (Basic Statistical Tests, n.d.). TOP rates after a terminal prenatal diagnosis and birth rates were analyzed using this method of analysis. The range, which obtains rate variation, was calculated for the analysis of TOP rates due to fetal abnormality and for birth rates and TOP rates due to fetal abnormality (Grinnell, Williams & Unrau, 2016).

As just noted, some of the data collected was used to find out if birth rates and abortions due to fetal abnormality changed after the enactment of perinatal hospice laws. This was done using an interrupted time series analysis and paired sample t-test- dependent samples. An interrupted time series analysis is a sequence of repeated data measurements, of one variable over time, which occurs before and after an intervention (Shadish, Cook & Campbell, 2002). This analysis measured TOP after a terminal diagnosis before and after enactment of the state law. Measuring before and after the perinatal hospice law will assess the impact of the law by assessing for change (Shadish, Cook & Campbell, 2002). TOP after a diagnosis of fetal abnormality and birth rates was also assessed using paired sample t-test- dependent samples, which is comparing two measurements within one group (Basic Statistical Tests, n.d.). The effect size was determined for Arizona and Minnesota paired samples t-test dependent samples using

Cohen's d. The reference values for Cohen's d are referred to as effect sizes, in which a small effect size is 0.1 - 0.2, medium is 0.3 - 0.4 and large is 0.5 - 0.6 (Cumming & Calin-Jageman, 2017).

Learning if informed consent laws have influenced birth and TOP rates due to fetal abnormality within the United States was the intention of this secondary dataset analysis. In addition to analyzing data, relevant research literature is examined. This includes a summary of what is known about perinatal hospice and pregnancy termination after a terminal prenatal diagnosis is given. The laws regarding both of these topics are explored and limitations within previous research discussed. Theoretical concepts relevant to this study are presented as well as research methods. The results from this analysis could lead to more effective interventions that support and empower families to make an informed choice after a devastating diagnosis during pregnancy. This study will explore the potential impact of perinatal hospice laws on family empowerment and decision making regarding a terminal prenatal diagnosis, measured by birth rates and TOP after a terminal prenatal diagnosis.

Findings of Previous Research

The following section will provide an overview about current knowledge on informed consent laws. A summary describing perinatal hospice laws will be presented so the reader has background knowledge about what perinatal hospice laws are, the regions within the United States it currently impacts and its importance. Relevant laws regarding abortion will be discussed so the reader is able to understand how this medical intervention option impacts families and providers after a terminal fetal diagnosis is given. Research literature regarding the advantages and disadvantages of choosing to continue a pregnancy and to terminate a pregnancy will be summarized. The limitations within the research will also be discussed. The literature review

aims to provide complete understanding about who is impacted by perinatal hospice laws, what they are intending to do, where they are enacted, when they came about and why laws were made to inform families about medical intervention options after a terminal prenatal diagnosis is made.

Perinatal Hospice

The concept of perinatal hospice began in 1996 as an alternative medical intervention to "partial birth abortion", in which the fetus is partially delivered, its head punctured, and the skull compressed before the fetus is completely removed from the mother (Calhoun, 2010). The perinatal hospice option after a terminal prenatal diagnosis was developed to provide better care to patients. Perinatal hospice empowers the family to influence the outcome in this unfortunate situation for the better, which tends to revolve around fear, isolation and abandonment when a diagnosis is given (Coleman, 2015). Termination may not be the preferred treatment for all parents; however, they may not be aware of alternative medical intervention choices after a terminal diagnosis is made. Pre-existing values and life philosophies may impact some families to choose and others to decline perinatal hospice services, religious beliefs influence over 10% of parents that choose to continue a pregnancy (Bourdens et al., 2017). The majority of the states across America have at least one organized perinatal hospice service. To date, perinatal hospice programming is available in all U.S. states except Maine, Nevada, Vermont and Wyoming (Perinatal Hospice & Palliative Care, 2018). Programming is available in states where legislation does not require information on this option to be given.

Informed consent. The six states that have perinatal hospice laws are similar in that they require perinatal hospice programming to be offered as an alternative to TOP but have variations within each of their statues (Arizona State Legislature, 2019; Indiana General Assembly, 2018;

Kansas State Legislature, 2018; Mississippi Legislature, 2019; Oklahoma State Department of Health, 2017; Office of the Revisor of State Statues, 2018). For example, the Arizona state statute says the physician who is to perform the abortion, or the referring physician has informed the woman, orally and in person, that perinatal hospice services are available, that the department of health services maintains a website that lists perinatal hospice programs available in Arizona and nationally and the woman has a right to review or obtain a printed copy of the materials free of charge (Arizona State Legislature, 2019). Whereas, the Minnesota statute states the physician who is to perform the abortion, or a referring physician needs to talk to the woman over the phone or in person, at least 24 hours before the abortion about the particular medical risks associated with the particular abortion procedure to be employed and must disclose to the woman any additional cost of the procedure for the administration of anesthetic or analgesic (Office of the Revisor of State Statues, 2018).

Perinatal hospice laws, or informed consent, is intended to be an in-depth discussion of medical intervention risks and advantages. This is meant to allow parents time for engagement, to reflect on the severity of the predicted condition and to determine the future impact of the treatment choice (Coleman, 2015). If perinatal hospice is chosen as an alternative medical intervention, the hospice team continues services with care coordination, delivery planning and assistance following birth. Supportive services provided by perinatal hospice programs are important for the parent's emotional health at the time of diagnosis, through pregnancy and after birth (Coleman, 2015). A complete understanding of the diagnosed conditions, prognosis and treatment options provided by perinatal hospice care theoretically empowers parents to make informed medical decisions. The focus of this report is to determine if perinatal hospice laws, or

informed consent, have promoted freedom of choice and respect parent's autonomy after a terminal prenatal diagnosis is made.

Perinatal hospice laws. Arizona, Kansas, Mississippi, Oklahoma, Indiana and Minnesota established laws mandating women receive perinatal hospice information after a diagnosis is made with the likelihood of the baby dying before or shortly after birth (Paquette, 2016). This alternative to abortion has been found to be chosen more often as a medical intervention as it becomes a known option (Bourdens, Tadonnet, Hostalery, Renesme, & Tosello, 2017). Challengers of perinatal hospice laws see it as "bogus" and an interference with women's reproductive rights (Guttmacher Institute, 2019). However, there has been consistency in an increasing trend of parents choosing perinatal hospice services (Bourdens et al., 2017; Hostalery & Tosello, 2017). This trend may be due to parents making an informed decision that is most suitable for them, which allows a healthy grieving process.

Minnesota was the first state to enact the informed consent law in 2006 (Culp-Ressler, 2014). The five other states followed suit, which may empower parents to make an educated decision about what is best for their family. They are in a situation where options are limited, and it is important to permit parenting (Sidgwick, Harrop, Kelly, Todorovic, & Wilkinson, 2017). Parenting, if desired, allows moments of the baby's life to be remembered in a positive way. Grief and medical instruction are the focus of the roughly 202 perinatal hospice programs in the United States (Edwards, 2018). These programs recognize that an unborn child is a part of the family and shared experiences are often important to parents. Programming outlines for the healthcare providers what rituals the family needs to participate in as they experience their grief (Bennett, Dutcher, & Snyders, 2011).

Termination of Pregnancy (TOP) After a Terminal Prenatal Diagnosis

The rate for detecting fetal abnormalities during mid to late pregnancy was found to be 72% accurate, with a false positive rate of 4% (Coleman, 2015). Prenatal testing is divided into non-invasive testing, such as an ultrasound used to detect physical deformities, and invasive testing, which screens for genetic abnormalities. Amniocentesis and chorionic villus sampling (CVS) are invasive tests that collect cells from the fetus, embryo or placenta (Vesely, 2018). Both of these testing methods have resulted in therapeutic abortions. Harvard Medical School (2019) defines therapeutic abortions as deliberately ending a pregnancy when there is a threat to the physical or mental health of the mother. This medical intervention is the "management of choice", in which ending life is the coping response to the suffering of a loved one (Lotto, Smith, & Armstrong, 2017). Some medical professionals claim TOP may help the parents minimize grief reactions or pathological grief reactions that is thought to be caused by continuing a pregnancy in which the baby is expected to die before or shortly after birth (Calhoun, 2010). However, there is no evidence that abortion reduces 'healthy' or pathological grief versus carrying the baby until birth or natural death (Côté-Arsenaulta & Denney-Koelschb, 2016).

TOP chosen as a medical intervention after a terminal prenatal diagnosis is the result of a multitude of factors, which makes it difficult to correlate the existence of perinatal hospice laws with outcomes. Prevention of emotional harm, personal desires for the child's quality of life, parenting concerns, balancing the needs of family members, potential financial problems and preventing suffering were found to be reasons to terminate (Gawron & Watson, 2018). The CDC defines an induced abortion as a voluntary intervention, performed by a licensed clinician, intended to prevent a live birth (Jatlaoui et al., 2016). Parents may choose this option in a state of distress when they are unclear about their decision, which has been found to create more suffering (Lafarge, Mitchell, & Fox, 2013). Parents also could feel pressured into making a

decision about a medical intervention as soon as possible. Adversaries of the perinatal hospice legislation see the requirement as another unnecessary control over these women who are already strained by their unfortunate circumstances (Cobb, 2015). The references used for this study only indicated the potential risks of grief and emotional well-being as impacting the mother if she chose to carry her child to term.

In North America, abortion politics include the selective use of pregnancy termination, which "muddies the water" since selective use of TOP is a different type of debate (Wolbring, 2016). This makes an already complex issue even more complicated and has resulted in varied research evidence. A participant in a study done by Gawron & Watson (2018) who chose TOP after a diagnosis of Trisomy 18 noted, "we decided that it was worth the emotional closure…maybe we're avoiding some mental health costs in the end…". Previous studies have found mixed outcomes regarding the effectiveness of TOP in reducing grief. Some parents have been found to experience relief and be at peace after choosing TOP (Kuebelbeck, 2003; Hooyman & Kramer, 2006). Other parents that chose TOP have experienced varied responses after the intervention. In many instances, parents have been found to experience a significant degree of grief, anxiety and post traumatic symptoms following their decision (Mashiach et al., 2013; Lafarge et al., 2013; Asplin, Wessel, Marions & Georgsson-Ohman, 2014; Cope, Garrett, Gregory & Ashley-Koch, 2015).

Abortion laws. Terminating a pregnancy is legal in the United States, however there are regulations and limitations within each state. Since the 1973 Supreme Court decision in Roe versus Wade, individual states have created a matrix of abortion laws (Guttmacher Institute, 2019). The specifications within each state decide if and when a woman's circumstances permit a legal abortion. It is interesting to note that a United States abortion survey dating back to 1980

argues TOP due to fetal abnormalities make up such small fraction of abortion cases, which makes a very poor premise to formulate general public policy regarding abortion (Johnston, 2016). With this being said, there are a multitude of current law variations surrounding abortion. These include, but are not limited to, the pregnancy trimester, requirements regarding the physician or medical professional, where the intervention is to be done, the method of termination, how it is paid for, waiting periods and/or mandated counseling (Guttmacher Institute, 2019).

In 45 states, health care providers have a choice to offer TOP as a medical intervention (Guttmacher Institute, 2019). When TOP is optional to provide, it is important health care professionals assess whether the medical intervention is an ethical option. This is because the parents, while in a state of shock and disorientation, may be vulnerable to suggestions or perceived suggestions that a treatment choice is the expected solution (Cobb, 2015). Application of ethical principles and virtues for every patient is to be honored by physicians, apart from the provider's own personal, religious and spiritual beliefs. This includes explanation of all treatment options especially since TOP can be seen as a 'social' choice the mother is entitled to make (Watt, 2017). The parents who receive a life limiting diagnosis for their unborn child are in a dependent state since they often lack necessary resources to care for the child. Parents who are in the midst of overwhelming difficulty create a responsibility to those directly caring for them to address getting their needs met (Cobb, 2015).

Gestation and legal TOP. Prohibiting a termination after a specific point in pregnancy, except when necessary to protect the woman's life or health is in effect in 43 states (Guttmacher Institute, 2019). Some states have established, that after the second trimester of pregnancy, TOP is no longer a legal option. The U.S. Supreme Court has retained that a state cannot ban TOP

before viability and that any restriction on TOP after viability needs exceptions to protect the health and life of the mother (Guttmacher Institute, 2019). Viability is defined by the Cambridge Dictionary (2019) as the ability to continue to exist or develop as a living being. Deciding to continue or terminate pregnancy after a fetal abnormality diagnosis takes time because of incorporating medical data with personal values while in a state of grief (Gawron & Watson, 2018). This type of abortion law impacts medical intervention decision making. When a late diagnosis of a presumably terminal fetal anomaly is made, these abortion laws potentially rush a medical intervention decision (Gawron & Watson, 2018).

The majority of pregnant women in the United States have reported receiving prenatal care during their first trimester of pregnancy. Prenatal care has reportedly been received by 77% of women, with the remaining women receiving care in their third trimester or not at all (Hamilton, Martin, Osterman, Driscoll, & Rossen, 2018). The majority of the nation receives prenatal care and it is important for providers to give their patients realistic options when a terminal diagnosis is made. Options for medical interventions provide empowerment and autonomy of the parents while receiving pregnancy guidance (Calhoun, 2010; Coleman, 2015).

Limitations of Previous Research

A limitation within the research literature are discrepancies about the length of time given to reflect on choosing a medical intervention. Researchers have reported that the duration of time given to decide on a treatment choice has been found not to matter (Flemming, Pehlke-Milde, Maurer & Parpan, 2016). In other literature the length of time between diagnosis and medical intervention was consistent. Coleman (2015) referenced a median amount of time in a study of 10,000 participants. This study concluded that “a reasonable amount of time” was necessary for informed decision making, permission for termination, referrals to specialists and waiting on test

results. “A reasonable amount of time” was reported to be an average of two weeks (Coleman, 2015).

Conceptual Framework

The perinatal hospice care continuum begins at diagnosis, typically in the prenatal setting, with support extending beyond the child’s believed life expectancy (Bennett et al., 2011). Perinatal hospice impacts how the baby's condition and prognosis is judged by parents because they are provided education on these topics. Medical intervention ideas can be exhausted, and parents are able to feel they have done as much as possible to help their child. Perinatal hospice outlines for providers what rituals the family needs to participate in as they experience their grief (Bennett et al., 2011). The interpretive framework, which is the approach to understanding the collected data, will be understood through the lens of empowerment theory and transpersonal theory. These theories will assist understanding if perinatal hospice laws promote freedom of choice and respect parent's autonomy after a terminal prenatal diagnosis is made.

Empowerment Theory

Perinatal hospice extends care to the loved ones of patients. An interdisciplinary team provides support in the form of education, which includes discussing medical interventions and development of a plan of care based on family wishes (Kamrath et al., 2018). A way to assist parents to confidently choose a medical intervention is by using the framework of empowerment theory. Empowerment theory develops engagement, informed decision making, collaboration, to be committed and to tolerate uncertainty (Johnson, 2011). It enables individuals to overcome their sense of powerlessness, lack of influence and to recognize resources. The intentional process of self-empowerment encourages individuals to take initiatives and be active in accomplishing goals. Belief in the ability to achieve goals, finish tasks and respond to challenges with competence, provides a sense of control in one’s life (Levenson, 2017).

Abilities and resources that relate to the growth of human potential and capacity are highlighted in empowerment theory. Coleman (2017) reported parents being able to access information to understand the prenatal diagnosis has helped reduce uncertainty and allow a feeling of control. This allows engagement, reflection on the severity of the predicted condition and gives time to determine the future impact of the treatment choice. A complete understanding of the condition, prognosis and treatment options provided by perinatal hospice care all influence self-mastery of parents. The level and the type of support health care professionals provide in this unfortunate situation is important for the parents' emotional health (Coleman, 2015). Using this theory enables collaborative partnerships between the interprofessional team and parents during end of life care.

Transpersonal Theory

Transpersonal theory is an incorporation of the spiritual dimension of the human experience (Robbins, Chatterjee & Canada, 2012). Perinatal hospice is holistic, and integration of this theory assists practitioners to understand the whole person and environment. Priorities, hopes and fears of parents are taken into consideration, which allows for shared decisions that respect values and support family needs (Sidgwick, Harrop, Kelly, Todorovic, & Wilkinson, 2017). The written birth plan allows parents to holistically outline what is important, what has meaning and explore all possible options. This theory extends to diverse populations and is consistent with the social justice orientation (Robbins, Chatterjee & Canada, 2012).

Transpersonal theory recognizes religious and spiritual diversity as an important aspect to the human experience (Robbins, Chatterjee & Canada, 2012). Perinatal hospice programming assists parents through complex influences, which often include spirituality and religion, to make an informed choice fitting their situation. Perinatal hospice programming recognizes the unborn child is a part of the family and shared experiences are often important to parents. It outlines for

the healthcare providers which practices the family would like to participate in while experiencing their grief (Bennett et al., 2011). States with perinatal hospice laws acknowledge self-efficacy by allowing the family to make choices that is most appropriate for them. Self-efficacy provides a sense of control since there is a belief in responding to challenges with competence (Levenson, 2017).

Methods

Research Design: Secondary Data Analysis

The research design used to find out if informed consent laws in the United States have made an impact on abortion rates due to fetal abnormalities was a secondary data analysis. The variables were the rates of births and the rates of abortions due to fetal abnormalities. Parents may pick TOP as a medical intervention because they might not be aware of alternative interventions. These same parents informed about perinatal hospice may choose this medical intervention that may have otherwise chosen TOP after the diagnosis of a fetal abnormality because they were not aware that it existed. This factor then changes birth rates and abortion rates due to fetal abnormalities. The variable controlled for was the perinatal hospice law.

Table 1

Central Research Question and Associate Research Questions

Research Questions	Hypothesis	Analysis Method
Central Research Question: Have perinatal hospice laws impacted TOP rates after a terminal prenatal diagnosis?	Yes, perinatal hospice laws have impacted TOP rates after a terminal prenatal diagnosis.	Associate research questions
Associate Research Question: Do states with perinatal hospice laws have different	Yes, states with perinatal hospice laws have different rates of TOP due to fetal	2 sample t-tests independent samples

TOP due to fetal abnormality rates than states without it?	abnormality than states without the law.	
Associate Research Question: Do states with perinatal hospice laws have different birth rates than states without it?	Yes, birth rates are different in states with perinatal hospice laws than in states without the law.	2 sample t-tests independent samples
Associate Research Question: Did TOP rates due to fetal abnormality change in states with perinatal hospice laws after enactment of the law?	Yes, TOP rates due to fetal abnormality changed in states with perinatal hospice laws after enactment of the law.	Interrupted time series and paired samples t-test dependent samples
Associate Research Question: Did birth rates change in states with perinatal hospice laws after enactment of the law?	Yes, birth rates changed in states with perinatal hospice laws after enactment of the law.	Interrupted time series and paired samples t-test dependent samples

Sample Population

The 15 states selected for analysis require TOP reporting for fetal abnormality (Guttmacher Institute, 2019). However, 6 of these states were excluded due to insufficient data. Oklahoma is not included due to the state suppression of this statistic (Oklahoma State Department of Health, n.d.). Washington state was excluded due to data being "not robust or reliable enough to use for research" (Washington State Department of Health, personal communication, April 8, 2019). New Jersey was omitted due to data being "very incomplete" (New Jersey Department of Health, personal communication, April 8, 2019). Hawaii, New York and West Virginia did not provide TOP due to fetal abnormality data nor did these health state departments respond to inquiry requests.

Perinatal Hospice Law States (PLS), Arizona and Minnesota refer to states that have perinatal hospice laws. States that do not have perinatal hospice laws and track TOP due to fetal abnormality are referred to as No Perinatal Hospice Law States (NPLS). Alaska, Florida, Louisiana, Nebraska, South Dakota, Utah and Virginia are the states referred to as NPLS. This research will find out if PLS promote freedom of choice and respect parent's autonomy after a terminal prenatal diagnosis, within the limitations of the available data.

Participants and Privacy Policy. Women who chose TOP after a terminal prenatal condition generated data for this project. The women are unidentifiable because the data is anonymous and from public sources.

Recruitment Process. Public sources were used for this secondary data analysis. The Center for Disease Control (CDC) collects data concerning the health of world populations and provides birth rate statistics (Jatlaoui, Mandel, Simmons, Suchdev, Jamieson & Pazol, 2016). Guttmacher Institute, a pro-choice agency, provides information about TOP and collects voluntary TOP data in the United States (Guttmacher Institute, 2019). The state departments of health in Arizona, Minnesota, Alaska, Florida, Louisiana, Nebraska, South Dakota, Utah and Virginia collect data from providers regarding why a TOP was performed and were used to gather TOP data due to fetal abnormality. Appendix 1 gives further information regarding the versions used and citations for each source.

Data Collection Process

The national data for birth rates for PLS and NPLS was collected from the CDC. Vital Statistics of the United States: 2001-2017 were the data sets used to collect birth rates. The rates of TOP due to fetal abnormality were gathered from state health departments in Arizona and Minnesota from 2001-2017 for PLS and Alaska, Florida, Louisiana, Nebraska, South Dakota,

Utah and Virginia 2006-2017 for NPLS. Again, see Appendix 1 for further information regarding the versions and citation for each year in each state used. The 9 states included in this study require reporting of a TOP due to fetal abnormality (Guttmacher Institute, 2019). The included states provide data on their websites or the data was sent via email after an inquiry to obtain this information was made. States that do not require this were not included because it is not known if the TOP was due to fetal abnormality or another reason. The data collection instrument was a secondary dataset of public information. Spreadsheets were created in Microsoft Excel to organize the collected data before analysis.

Data Analysis

Microsoft Excel was used for data analysis of all collected numerical information. The mean rate and standard deviation of TOP due to fetal abnormality in PLS and NPLS was calculated. The t value, p value and Cohen's d were then calculated. All of these calculations were done for the two-sample t test- independent samples and for the paired sample t test- dependent samples. Additionally, two-line graphs were made for the time series analysis. This visual display shows trends in birth rates and TOP after diagnosis of fetal abnormality rates pre and post establishment of perinatal hospice laws in Minnesota and Arizona.

Independent Samples

A spreadsheet was made in Microsoft Excel to organize the data used for analysis of the two-sample t test- independent samples. The years included in this analysis ranged from 2006-2017. One spreadsheet was used to organize TOP after fetal abnormality in PLS, TOP after fetal abnormality in NPLS, birth rates in NPLS and birth rates in PLS. The sample t-tests independent samples analysis included the years 2006 – 2017. The year 2006 was chosen because it was the year of the first perinatal hospice law in effect and 2017 was chosen because it was the most recent data available.

PLS/NPLS TOP due to fetal abnormality. The first spreadsheet was used to organize TOP after fetal abnormality in Arizona and Minnesota. Data from the Arizona and Minnesota Departments of Health were marked accordingly on the spreadsheet. It should be noted that Arizona did not collect data regarding TOP due to fetal abnormality in 2010. The spreadsheet represents this gap in data by a blank cell for Arizona during 2010. The first two sample t-tests independent samples compared the average TOP rate due to fetal abnormality in PLS to the average TOP rate due to fetal abnormality in NPLS.

Table 2

TOP due to fetal abnormality in PLS Independent Samples Data

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
AZ	8	2	4	19	*	97	85	141	123	120	110	100
MN	162	155	150	160	182	204	171	193	188	194	174	178
Total	170	157	154	179	182	301	256	334	311	314	284	278

*AZ did not provide data for 2010

Data from the corresponding NPLS departments of health (Alaska, Florida, Louisiana, Nebraska, South Dakota, Utah and Virginia Departments of Health) was marked accordingly on the spreadsheet. It should be noted that Louisiana did not collect data in 2013 or 2014 and Virginia did not collect data from 2015-2017. The spreadsheet represents these gaps in data with blank cells for Louisiana in 2013 and 2014 and for Virginia from 2015-2017.

Table 3

TOP due to fetal abnormality in NPLS Independent Samples Data

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
AK	1	7	7	5	2	9	4	3	6	6	3	1
FL	676	463	511	515	526	575	533	500	562	502	494	625
LA	2	1	0	2	1	53	54	**	**	70	37	36
NE	25	24	8	26	30	11	19	19	16	15	22	16
SD	16	0	14	12	7	7	3	3	10	6	6	2
UT	32	20	33	34	49	42	27	27	35	40	41	35
VA	114	131	128	134	106	118	103	85	94	***	***	***
Total	866	646	701	728	721	815	743	637	723	639	603	715

** LA did not provide data for 2013 or 2014 ***VA did not provide data for 2015- 2017

The totals for TOP due to fetal abnormality in PLS and NPLS were then organized on spreadsheets according to the year the data was collected by the Department of health for the states listed in Table 2 and Table 3.

Table 4

TOP Due to Fetal Abnormality Independent Samples Data

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
PLS	170	157	154	179	*	301	256	334	311	314	284	278
NPLS	866	646	701	728	721	815	743	637	723	639	603	715
Total	1,036	803	855	907	721	1,116	999	971	1,034	953	887	993

*2010 PLS left blank due Arizona not providing data

PLS/NPLS birth rates. Birth rate data from the CDC was entered to correspond with the NPLS and PLS accordingly on the Excel spreadsheet as seen in Table 4. A second two sample t-tests independent samples compared the average birth rate in PLS to the average birth rate in NPLS as seen in Table 5 below.

Table 5

Birth Rate Independent Samples Data

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
PLS	175,954	174,060	172,086	166,524	155,860	153,777	154,944	154,738	156,919	155,219	154,269	150,467
NPLS	511,141	519,346	508,947	495,132	481,808	478,619	479,598	481,412	489,276	493,728	491,197	482,024
Total	687,095	693,406	681,033	661,656	637,668	632,396	634,542	636,150	646,195	648,947	645,466	632,491

Dependent Samples

The date range selected for the paired samples t-test dependent samples incorporates data from five years prior to the first perinatal hospice law enacted through the most recent year of collected data. This ranges from 2001 – 2017. 2001 is five years prior to Minnesota establishing the first perinatal hospice law and 2017 is the most recent available data. Each year of reported data represents one data point, which provides five-data points for analysis of the paired samples t-test dependent samples. Five-data points were chosen because results from a five-point single-subject design allows for guidance community improvements (Grinnell, Williams & Unrau, 2016).

A second spreadsheet was made in Microsoft Excel to organize the data used for analysis of the paired sample t test- dependent samples. The years included in this analysis ranged from 2001-2017. This spreadsheet was used to organize TOP after fetal abnormality in PLS, TOP after fetal abnormality in NPLS, birth rates in NPLS and birth rates in PLS. The years included in this analysis ranged from 2001-2017.

TOP rate after a terminal prenatal diagnosis in PLS. Paired samples t-test dependent samples compared the average TOP rate due to fetal abnormality in PLS before and after enactment of the perinatal hospice law. The TOP rate after a diagnosis of fetal abnormality mean, standard deviation, t value, p value and Cohen's d were all calculated for Arizona. These same calculations were conducted for Minnesota.

The second spreadsheet was used to organize TOP due to fetal abnormality in Arizona and Minnesota. Data from the Arizona and Minnesota Departments of Health was marked accordingly on the spreadsheet. It should be noted that Arizona did not collect data regarding

TOP due to fetal abnormality in 2010. The spreadsheet represented this gap in data by a blank cell for Arizona during 2010.

Table 6

TOP Due to Fetal Abnormality

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
AZ	10	21	43	207	78	8	2	4	19		97	85	141	123	120	110	100
MN	158	113	146	133	129	162	155	150	160	182	204	171	193	188	194	174	178
Total	168	134	189	340	207	170	157	154	179	182	301	256	334	311	314	284	278

PLS birth rates. A second paired samples t-test dependent samples compared birth rates in PLS before and after the law. The birth rate mean, standard deviation, t value, p value and Cohen's d were all calculated. These same calculations were conducted for Minnesota. Birth rate data from the CDC was entered to correspond with Arizona and Minnesota accordingly on this second spreadsheet.

Table 7

Birth Rates 2001-2017

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
AZ	85,597	87,837	90,967	93,663	96,199	102,429	103,646	99,873	92,925	87,555	85,533	86,650	85,988	87,310	85,701	84,520	81,872
MN	67,562	68,025	70,050	70,624	70,919	73,525	70,414	72,213	73,599	68,305	68,244	68,294	68,750	69,609	69,518	69,749	68,595
Total	153,159	155,862	161,017	164,287	167,118	175,954	174,060	172,086	166,524	155,860	153,777	154,944	154,738	156,919	155,219	154,269	150,467

Time Series Analysis

A third spreadsheet for Arizona and Minnesota was made for the time series analysis and included the years 2001 – 2017. Two interrupted time series analysis graphs were made with the date range from 2001-2017. Arizona and Minnesota are the PLS used for this analysis. The graphs compared the TOP rate due to fetal abnormality and birth rates in PLS. They show TOP rates due to fetal abnormality and birth rate data that was collected before and after enactment of the law. They were made color coded with 6 different colors. Blue represented the MN pre law

rates, orange represented MN post law rates, grey represented AZ pre law rates and yellow represented AZ post law rates. The purple horizontal line represents the establishment of the perinatal hospice law in Minnesota and the green horizontal line represents the establishment of the perinatal hospice law in Arizona. Birth rate data from the CDC was entered to correspond with Arizona and Minnesota accordingly on the spreadsheet and converted into a line graph.

Findings

Associate Research Questions 1 & 2: Do PLS Have Different Birth & TOP Rates Due to Fetal Abnormality Than NPLS?

Table 8

Two Sample T-Test Independent Samples Results for TOPs and Birth Rates of PLS & NPLS

	PLS		NPLS				
	M	SD	M	SD	t	p	Cohen's d
TOPs	243.33	69.31	710.67	75.66	2.2	1.77	0.64
Births	160,401.42	9,065.94	492,685.67	13,701.24			

The average rate of TOP after a fetal abnormality is detected was higher in NPLS (M=710.67) than in PLS (M=243.33). The high SDs of 69.31 in PLS and 75.66 in NPLS indicate that the data points are not consistent, which means this measurement is not very reliable. The range for TOP due to fetal abnormality was found to be 395. 61,010 was the birth rate range. Birth rates in PLS were found to have a lower average (M=160,401.42) than in NPLS

(M=492,685.67). Again, the high SDs of 9,065.94 in PLS and 13,701.24 in NPLS indicate that the data points are not consistent, which means this measurement is not very reliable.

A t value of 2.2 indicates that the coefficient is significant with a 95% confidence level because it is greater than 2. A p value of 1.77 represents this study to not be statistically significant. This is because the p value is higher than 0.05. The null hypothesis has been rejected, meaning a change between PLS and NPLS in the rate of TOPs after a terminal prenatal diagnosis and a change in birth rates may have occurred by chance. Cohen's d of 0.64 indicates the effect size is considered to be medium because it is greater than 0.5 and less than 0.8. The medium effect size indicates that there is a change in the average rate of TOPs after a terminal prenatal diagnosis and birth rate between PLS and NPLS. However, these results are not statistically significant, and it is possible that these results may be due to chance.

Associate Research Questions 3 & 4: Did Birth & TOP Rates Due to Fetal Abnormality Change in PLS After Law Enactment?

Table 9

AZ Results for Birth & TOP Due to Fetal Abnormality After Law Enactment

	Before Law		After Law				
	M	SD	M	SD	t	p	Cohen's d
TOPs	48.9	64.35	113.17	19.47	2.09	0.72	0.17
Births	93,293.09	6559.07	85,340.17	1941.47			

In the state of Arizona, the average rate of pregnancy termination after an abnormality is detected was higher after the establishment of a perinatal hospice law (M=113.17) than before the law was established (M=48.9). The SD of 19.47 post law establishment and the SD of 64.35 pre law establishment indicates the data points are not consistent, which means this measurement is not very reliable. Birth rates within Arizona were found to have a lower average (M=85,340.17) after the law was established than before the law (M=93,293.09). The SD of 1,941.47 post law indicates and the SD of 6,559.07 pre law indicates the data points are not consistent, which means this measurement is not very reliable.

A t value of 2.09 indicates that the coefficient is significant with a 95% confidence level because it is greater than 2. A p value of 0.72 represents this study to not be statistically significant. This is because the p value is higher than 0.05. The null hypothesis has been rejected, meaning a change in the rate of TOPs after a terminal prenatal diagnosis and a change in birth rates may have occurred by chance before and after the establishment of the perinatal hospice law. Cohen's d of 0.17 indicates that indicates the effect size is considered to be small because it is less than 0.5. The small value of 0.17 represents a trivial change in the rates of birth and TOP due to fetal abnormality before and after establishment of the perinatal hospice law in Arizona. However, these results are not significant, and the results may be due to chance.

Table 10

MN Results for Birth & TOP Due to Fetal Abnormality After Law Enactment

Before Law		After Law				
M	SD	M	SD	t	p	Cohen's d

TOPs	135.8	17.11	175.92	16.99	2.67	0.98	0.65
Births	69,436	1,540.33	70,067.92	1,982.33			

In the state of Minnesota, the average rate of pregnancy termination after an abnormality is detected was higher after the establishment of a perinatal hospice law (M=175.92) than before the law was established (M=135.80). The SD of 16.99 post law establishment and the pre law establishment SD of 17.11 indicates that the data points are not consistent, which means this measurement is not very reliable. Birth rates within Minnesota were found to have a higher average (M=70,067.92) after the law was established than before the law (M=69,436.00). The SD of 1,982.33 post law and the pre law establishment SD of 1,540.33 indicates the data points are not consistent, which means this measurement is not very reliable. The range was found to be 200 for the total TOP due to fetal abnormality and the range for total birth rates was 25,487.

A t value of 2.67 indicates that the coefficient is significant with a 95% confidence level because it is greater than 2. A p value of 0.98 represents this study to not be statistically significant. This is because the p value is higher than 0.05. The null hypothesis has been rejected again, meaning a change in the rate of TOPs after a terminal prenatal diagnosis and a change in birth rates may have occurred by chance before and after the establishment of the perinatal hospice law. Cohen's d of 0.65 indicates the effect size is considered to be medium because it is less than 0.8. The medium effect size indicates that there has been a change in the average rate of TOPs after a terminal prenatal diagnosis and birth rates in Minnesota since the establishment of perinatal hospice laws. However, these results are not significant, and the results may be due to chance.

Interrupted Time Series
Figure 1

TOP Due to Fetal Abnormality Interrupted Time Series

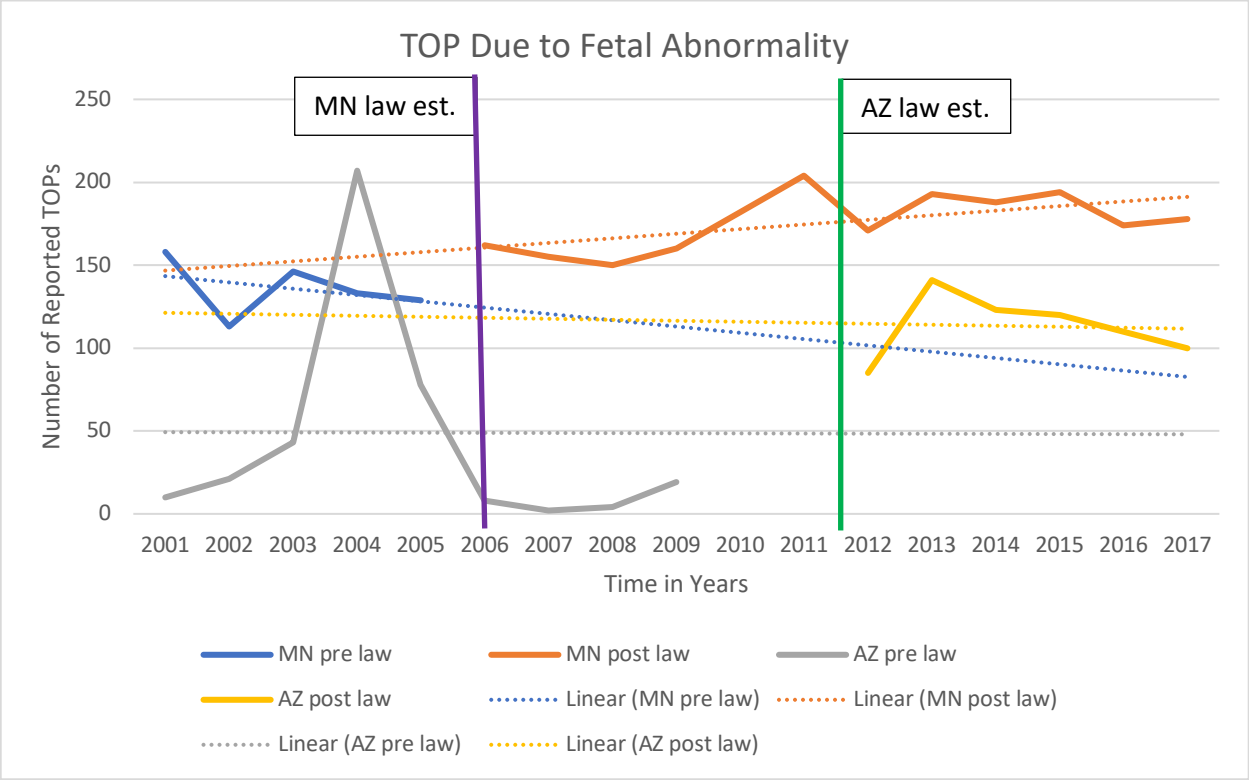

Figure 1 trend line analysis. It appears the Minnesota rates of TOP due to fetal abnormality rose since 2005, which is the year prior to the law being established. The rate of TOP due to fetal abnormalities in Minnesota before the establishment of the perinatal hospice law appears to show a decreasing trend, except for 2002-2003, in which the trend increased.

Prior to 2012 when the establishment of perinatal hospice laws went into effect, Arizona's trend in TOP due to fetal abnormalities appears to be quite erratic, especially from 2003-2006. In 2004, Arizona reported 207 TOPs due to fetal abnormality, which is an outlier. Figure 1 shows a clear increase in TOP due to fetal abnormality from 2012-2013 and then appears to show a rate decrease. Regression to the mean is doubtful because the 11 years prior to

the law shows a sharp increase in TOP due to fetal abnormality from 2003-2004, a sharp decrease from 2004-2006 and then an increase from 2007-2009 (Shadish, Cook & Campbell, 2002). It is possible that there is a threat to the internal validity to the Arizona data because it does not provide a clear picture of the trend before or after establishment of the perinatal hospice law. The validity could be compromised because of instrumentation and how records were kept (Shadish, Cook & Campbell, 2002).

Figure 2

Birth Rates in PLS Interrupted Time Series

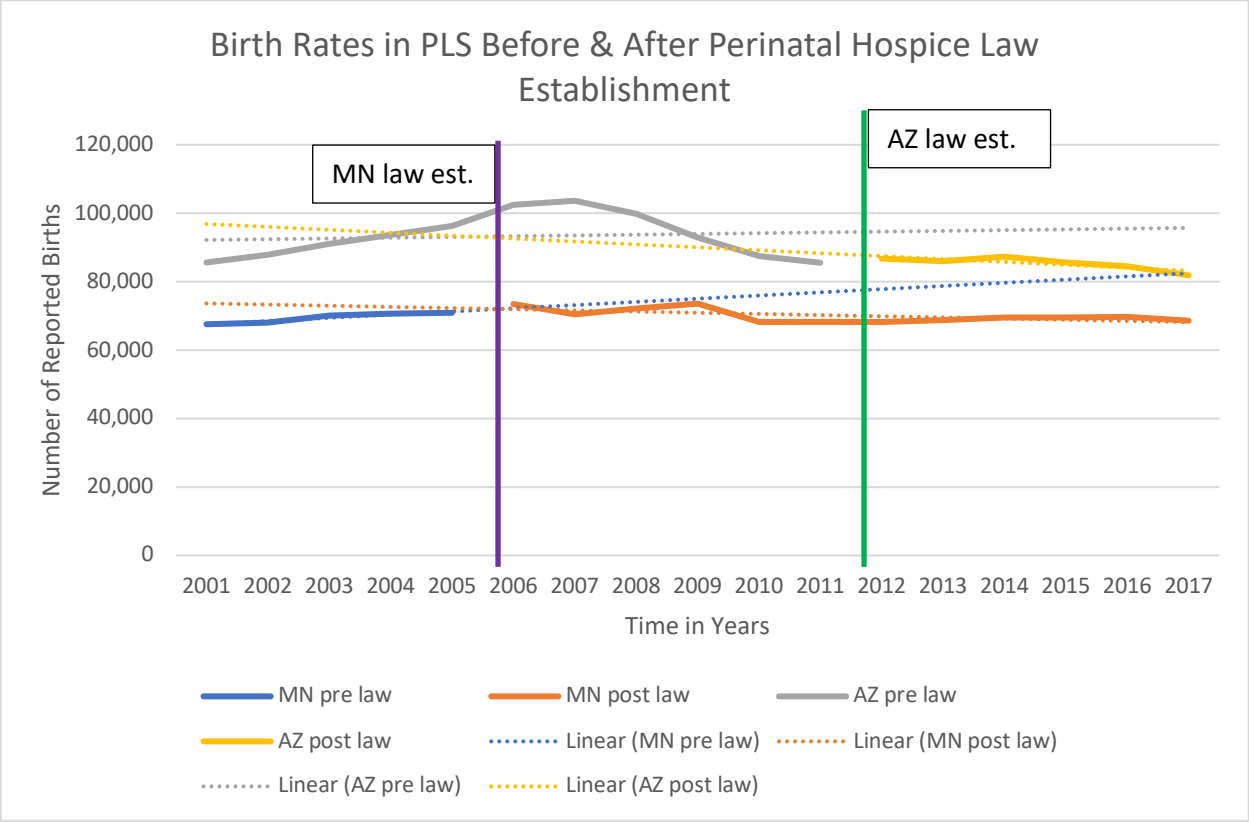

Figure 2 trend line analysis. Figure 2 depicts the birth rate trend line to appear to increase before the establishment of a perinatal hospice law in both Minnesota and Arizona. The

birth rate trend line in both states also both appear to decrease after each state established a perinatal hospice law.

Discussion

What Do These Findings Mean?

The findings from this study indicate that there needs to be more research done on the impact of perinatal hospice laws. The medium effect size of Cohen's d found in the two-sample t-test independent samples and in the Minnesota paired samples t-test dependent samples analysis show that there is a change because of an established perinatal hospice law. The small effect size of Cohen's d in the Arizona paired samples t-test dependent samples analysis conclude the change because of the established perinatal hospice law is minute. The answer to the CRQ: it appears that there could be a change as the data did show a trend in this area, however more research is necessary due to the lack of statistical significance in the findings of this study.

Table 11

Associate Research Question Findings

Associate Research Questions	Findings
Do states with and without perinatal hospice laws have different rates of TOP due to fetal abnormality?	States with and without perinatal hospice laws have different rates of TOP due to fetal abnormality. However, the results were not statistically significant.
Do states with perinatal hospice laws have different birth rates than states without the law?	Birth rates are different in states with perinatal hospice laws than in states without the laws. However, the results were not statistically significant.

Did TOP rates due to fetal abnormality change in states with perinatal hospice laws after enactment of the law?	TOP rates due to fetal abnormality changed in Minnesota after enactment of the law. However, the results were not statistically significant.
Did birth rates change in states with perinatal hospice laws after enactment of the law?	Birth rates changed in Minnesota after enactment of the law. However, the results were not statistically significant.

A factor to consider when interpreting these results is the possibility of a type two error. Factoring this would indicate perinatal hospice laws are impacting TOP rates due to fetal abnormality and birth rates even though the results are not significant. Another interesting addition to the interpretations of these research findings are the trend lines in Figure 11 and Figure 12. These birth rate trends could be due to a multitude of factors such as birth rates on the decline, as a whole, across the United States, incomplete data and a declining fertility rate in the United States (Nargund, 2009). Factors such as social structure, religious beliefs, economic prosperity and urbanization impact both the TOP rates and birth rates, which also may have an impact on the trend lines displayed in this research (Nargund, 2009).

How do The Findings Relate to the Literature Review?

The results from this study seem really unexpected when looking through the lenses of empowerment and transpersonal theories. The benefits of making an informed choice, additional emotional support during a life struggle and beginning grief in a healthy way gives the impression that perinatal hospice laws would significantly decrease TOP after detecting a fetal abnormality. This is especially true when compared with international studies, such as those from France. Alternative medical interventions to abortion are gradually being used more and

more. So much so that the use of perinatal hospice care was found to increase 37% over a 9-year period (Bourdens, Tadonnet, Hostalery, Renesme, & Tosello, 2017).

A study from Sweden explored pregnant women's experiences after a fetal abnormality was detected by ultrasound. It is interesting to note the Swedish mothers found the prenatal diagnosis information to be "uncertain, confusing and inadequate" (Coleman, 2015). This same research found the women who chose to terminate their pregnancy felt there was a lack of communication and corporation between care units, which resulted in them feeling the post termination information they were given was substandard. Another assessment angle that expands the surprising results is from the ablest perspective. A study from Canada found individuals that identify as having a disability and parents of differently abled children are outraged by TOP due to disabilities discovered during prenatal testing (Vesely, 2018). Some individuals to interpret this medical intervention as a form of eugenics and a blatant attack against people with disabilities.

Implications for Social Work Practice

Seemingly routine prenatal screening often detects fetal abnormalities, which is often unexpected by parents. Coleman (2017) reported parents being able to access information to understand the diagnosis has helped reduce uncertainty and allow a feeling of control for parents after a fatal prenatal diagnosis. Perinatal hospice allows for diagnostic and prognostic understanding along with exhaustion of medical intervention ideas, so parents are able to feel they have done as much as possible to help their child. Even though this is a relatively new concept of care, the majority of families that have experienced perinatal hospice report a strengthened and enriched family relationship, regardless of how long the child lived (Coleman, 2015). Relationship establishment and relationship building is a core theme among social work

practice and parallels the same relational aspects involved in perinatal hospice care. Valuing the importance of relationships is cited as an ideal to strive for as well as an ethical principal on the NASW code of ethics (2008).

Program growth. With this being said, there is room for the growth of perinatal hospice programming within social work practice. There are currently gaps in resources to provide this type of service since the establishment of perinatal hospice laws. Perinatal hospice is a developing subspecialty within pediatric medicine (Sidgwick, Harrop, Kelly, Todorovic & Wilkinson, 2017). Since this is a specialty area of service, there are not many social workers, or medical personnel for that matter, that have expertise in this area. Additionally, perinatal hospice care work is usually not full-time, so development, growth and maintenance of such programs are in need of support (Perinatal Hospice & Palliative Care, 2018).

Following models. Multidisciplinary holistic support that is patient-focused with non-judgmental shared decision making are the key aspects of a perinatal hospice model (Sidgwick et al., 2017). Following a previously established models is a way to continue growing this type of program in areas of the country where it is needed. The additional layer of support necessary for "hospice in the womb" is described by Perinatal Hospice and Palliative Care (2018) as "easily incorporated" into standard pregnancy and birth care. This unexpected journey, which is unimageable for many, requires medical professionals to be willing to walk alongside families during such a challenging life experience. St. Gianna Molla describes assisting others during these sacred experiences, from the earliest moments to the final moments of life, as honorable (Masterson & Masterson, 2005).

Policy Implications

Hopefully, perinatal hospice laws will be viewed as a social justice issue and not a restriction on women's reproductive rights. This topic is much deeper than that and needs to be

treated as so because of the complexity of this topic. Within American culture, the term "disabled" has been interpreted as "unable" to fully participate in society due to the dichotomy of "normal" and pathological (Vesely, 2018). The ableist perspective expects every human to look and act a certain way. Each society has different hierarchies about which social groups they accept and when the unacceptable is seen through a disease narrative it is eliminated (Wolbring, 2016). The elimination of unacceptable humans, which is accomplished by TOP due to fetal abnormality, is a possible trend that is occurring in Minnesota as seen in Figure 1, however the results from this study are not statistically significant and could be due to change. Marty and Carter (2018) found medical intervention decisions are based on diagnostic certainty, prognostic certainty and the prognostic meaning to the family. Continuing a pregnancy or terminating after an abnormal fetal diagnosis has social justice issues woven deeply into the medical intervention decision.

Lack of resources seem to have impact on the decision to terminate a pregnancy as discussed in Gawron and Watson (2018). However, there are often many other motivators for continuing a pregnancy after a terminal prenatal diagnosis. Religion beliefs are a contributing factor in over 10% of parents that choose to continue a pregnancy, however factors such as pre-existing values and philosophies about life and ethics may cause some families to choose, and others to decline perinatal hospice (Bourdens et al., 2017). In any circumstance, choosing a medical intervention after this type of diagnosis is an incredibly complex decision that acknowledges our interdependence on one another. Access to needed information, services and resources; equality of opportunity; and meaningful participation in decision making for all people is a process that perinatal hospice laws are striving for and also social work principle that is constantly perused (NASW, 2008).

Research Implications

A study in which the time frame is longer to obtain data that was not attainable during a semester time frame would be beneficial to this short project that has scratched just the surface of this topic. There was not research found which identified who is using perinatal hospice services. It would be interesting to find out if there are identifying characteristics of the population this service assists, which could be accomplished during an extended time frame. The states that were excluded from this study could potentially be used if a longer period of time were used to peruse data from the states that did not respond to email inquiries. More time would also allow the possibility to further investigate Arizona's erratic data reporting of TOP after a diagnosis of fetal abnormality as seen in Table 2. A longer time frame would also allow exploration of the impact of the increase in immigrant populations in Arizona and Minnesota. It is important that research continue so this type of law, one that offers parents the opportunity to fully participate in significant decision making, is not seen as "bogus".

Strengths and Limitations

Well researched. Even with perinatal hospice being a relatively new concept, there is a vast amount of research that has been conducted globally on the impact of the impact of its use. A strength of the research literature reviewed is that there is a lot of information about the trend of women being at risk for prolonged mental health conditions following TOP due to a terminal prenatal diagnosis. This complex issue has been debated, studied and reported on from all across the world (Coleman, 2015). It is fascinating that the topic is being looked at from a global level with similar results following studies. There is also consistency in the trend of an increased use of perinatal hospice services as it becomes a known medical intervention (Bourdens et al., 2017; Hostalery and Tosello, 2017).

Incomplete data. A major limitation to this research project was collecting secondary data that was not entirely complete, as seen in Table 2 and Table 3. Arizona, Louisiana and Virginia did not provide complete data for TOP due to fetal abnormality during the date ranges analyzed. Arizona was unable to supply data for 2010, Louisiana for 2014 and 2014 and Virginia from 2015-2017. Also, six of the 15 states that were reported to collect data regarding TOP due to fetal abnormality were rejected as reliable sources due to having insufficient records. Another limitation to this research is that there was not data available which presented information about the use of perinatal hospice programming in areas without legislation requiring information to be given.

Conclusion

Perinatal hospice is end of life care for an unborn baby when the child's life expectancy is less than six-months. This programming is a way of caring for the pregnant mother, the baby, the father and all involved with dignity, compassion and love as they journey through pregnancy, birth and death to honor the baby and the baby's family (Perinatal Hospice & Palliative Care, 2018). Arizona, Kansas, Mississippi, Oklahoma, Indiana and Minnesota have established laws mandating women receive perinatal hospice information after a diagnosis is made with the likelihood of the baby dying before or shortly after birth. Perinatal hospice was developed as an alternative to TOP, which is a widely supported and chosen medical intervention for fetal abnormalities (Lotto, Smith, & Armstrong, 2017).

This secondary dataset analysis aimed to find out if informed consent laws in the United States have made an impact on birth and abortion rates after a terminal prenatal diagnosis. It was found, within the data used in this research, that there has been a change in the rate of TOP due to fetal abnormality but could be due to chance because of the lack of statistical significance and inconsistencies with available data. A medical intervention decision made in this type of

situation is incredibly complex and deserves to be treated as so. What you cannot turn to good, you must at least make as little bad as you can – St. Thomas More.

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Appendix A

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Tables

Table 1

Central Research Question and Associate Research Questions

Research Questions	Hypothesis	Analysis Method
Central Research Question: Have perinatal hospice laws impacted TOP rates after a terminal prenatal diagnosis?	Yes, perinatal hospice laws have impacted TOP rates after a terminal prenatal diagnosis.	Associate research questions
Associate Research Question: Do states with perinatal hospice laws have different TOP due to fetal abnormality rates than states without it?	Yes, states with perinatal hospice laws have different rates of TOP due to fetal abnormality than states without the law.	2 sample t-tests independent samples
Associate Research Question: Do states with perinatal hospice laws have different birth rates than states without it?	Yes, birth rates are different in states with perinatal hospice laws than in states without the law.	2 sample t-tests independent samples
Associate Research Question: Did TOP rates due to fetal abnormality change in states with perinatal hospice laws after enactment of the law?	Yes, TOP rates due to fetal abnormality changed in states with perinatal hospice laws after enactment of the law.	Interrupted time series and paired samples t-test dependent samples
Associate Research Question: Did birth rates change in states with perinatal hospice laws after enactment of the law?	Yes, birth rates changed in states with perinatal hospice laws after enactment of the law.	Interrupted time series and paired samples t-test dependent samples

Table 2

TOP due to fetal abnormality in PLS Independent Samples Data

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
AZ	8	2	4	19	*	97	85	141	123	120	110	100
MN	162	155	150	160	182	204	171	193	188	194	174	178
Total	170	157	154	179	182	301	256	334	311	314	284	278

*AZ did not provide data for 2010

Table 3

TOP due to fetal abnormality in NPLS Independent Samples Data

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
AK	1	7	7	5	2	9	4	3	6	6	3	1
FL	676	463	511	515	526	575	533	500	562	502	494	625
LA	2	1	0	2	1	53	54	**	**	70	37	36
NE	25	24	8	26	30	11	19	19	16	15	22	16
SD	16	0	14	12	7	7	3	3	10	6	6	2
UT	32	20	33	34	49	42	27	27	35	40	41	35
VA	114	131	128	134	106	118	103	85	94	***	***	***
Total	866	646	701	728	721	815	743	637	723	639	603	715

** LA did not provide data for 2013 or 2014 ***VA did not provide data for 2015- 2017

Table 4

TOP Due to Fetal Abnormality Independent Samples Data

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
PLS	170	157	154	179	*	301	256	334	311	314	284	278
NPLS	866	646	701	728	721	815	743	637	723	639	603	715
Total	1,036	803	855	907	721	1,116	999	971	1,034	953	887	993

*2010 PLS left blank due Arizona not providing data

Table 5

Birth Rate Independent Samples Data

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
PLS	175,954	174,060	172,086	166,524	155,860	153,777	154,944	154,738	156,919	155,219	154,269	150,467
NPLS	511,141	519,346	508,947	495,132	481,808	478,619	479,598	481,412	489,276	493,728	491,197	482,024
Total	687,095	693,406	681,033	661,656	637,668	632,396	634,542	636,150	646,195	648,947	645,466	632,491

Table 6

TOP Due to Fetal Abnormality

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
AZ	10	21	43	207	78	8	2	4	19		97	85	141	123	120	110	100
MN	158	113	146	133	129	162	155	150	160	182	204	171	193	188	194	174	178
Total	168	134	189	340	207	170	157	154	179	182	301	256	334	311	314	284	278

Table 7

Birth Rates 2001-2017

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
AZ	85,597	87,837	90,967	93,663	96,199	102,429	103,646	99,873	92,925	87,555	85,533	86,650	85,988	87,310	85,701	84,520	81,872
MN	67,562	68,025	70,050	70,624	70,919	73,525	70,414	72,213	73,599	68,305	68,244	68,294	68,750	69,609	69,518	69,749	68,595
Total	153,159	155,862	161,017	164,287	167,118	175,954	174,060	172,086	166,524	155,860	153,777	154,944	154,738	156,919	155,219	154,269	150,467

Table 8

Two Sample T-Test Independent Samples Results for TOPs and Birth Rates of PLS & NPLS

	PLS		NPLS				
	M	SD	M	SD	t	p	Cohen's d
TOPs	243.33	69.31	710.67	75.66	2.2	1.77	0.64
Births	160,401.42	9,065.94	492,685.67	13,701.24			

Table 9

AZ Results for Birth & TOP Due to Fetal Abnormality After Law Enactment

	Before Law		After Law				
	M	SD	M	SD	t	p	Cohen's d
TOPs	48.9	64.35	113.17	19.47	2.09	0.72	0.17
Births	93,293.09	6559.07	85,340.17	1941.47			

Table 10

MN Results for Birth & TOP Due to Fetal Abnormality After Law Enactment

	Before Law		After Law				
	M	SD	M	SD	t	p	Cohen's d
TOPs	135.8	17.11	175.92	16.99	2.67	0.98	0.65
Births	69,436	1,540.33	70,067.92	1,982.33			

Table 11

Associate Research Question Findings

Associate Research Questions	Results of Findings
Do states with and without perinatal hospice laws have different rates of TOP due to fetal abnormality?	Yes, states with and without perinatal hospice laws have different rates of TOP due to fetal abnormality. However, the results were not statistically significant.
Do states with perinatal hospice laws have different birth rates than states without the law?	Yes, birth rates are different in states with perinatal hospice laws than in states without the laws. However, the results were not statistically significant.
Did TOP rates due to fetal abnormality change in states with perinatal hospice laws after enactment of the law?	Yes, TOP rates due to fetal abnormality changed in Minnesota after enactment of the law. However, the results were not statistically significant.

Did birth rates change in states with perinatal hospice laws after enactment of the law?	Yes, birth rates changed in Minnesota after enactment of the law. However, the results were not statistically significant.

Figures

Figure 1

TOP Due to Fetal Abnormality Interrupted Time Series

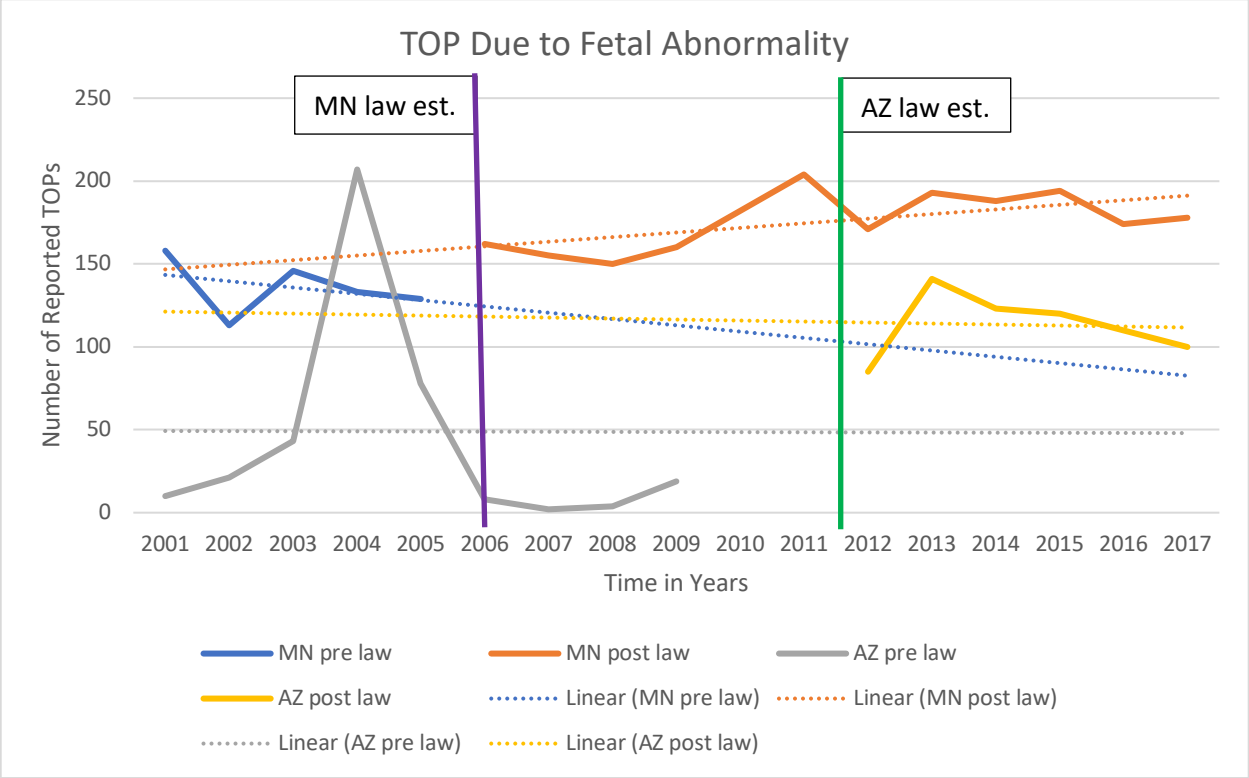

Figure 2

Birth Rates in PLS Interrupted Time Series